# "This is the worst that has happened to me in 86 years": A qualitative study of the experiences of grandparents losing a grandchild due to a neurological or oncological disease

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Abstract: Purpose Pediatric palliative care focuses mainly on the children suffering from a life-limiting disease, but always includes parents and siblings. However, grandparents are also often highly involved in caring for the child and require additional attention. Therefore, the aim of this study was to investigate the experiences of grandparents during the end-of-life care and after the death of a grandchild. Design and Methods A qualitative approach using semi-structured interviews was chosen. Fifteen grandparents of 10 children who had died of neurological or oncological diseases were interviewed. Participants were recruited among the families cared by the pediatric palliative care team of a children's hospital in northern Switzerland. Grandparents were interviewed at least 1 year after the death of the grandchild. The data was analyzed employing reconstructive interview analysis. Results Regardless of the child's diagnosis and circumstances of death, the participants described how the child's death had a major impact on them and their entire family. Grandparents felt obligated to support the family and constantly be a source of support for the parents. They bore a heavy psychological burden as they cared and mourned not only for their dying grandchild but also for their own daughter or son. Grandparents struggled with their ability to communicate about disease and death. They tried to process and make sense of their loss by remembering the deceased child. Practice Implications These findings emphasize the importance of identifying and understanding grandparents' suffering. Pediatric palliative care teams can achieve this by actively making contact with grandparents, taking their concerns seriously and demonstrating appreciation for their role in supporting the family.

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# “I don’t want this to be in my biography”: A qualitative study of the experiences of grandparents losing a grandchild due to a neurological or oncological disease

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**Abstract**

**Purpose:** Pediatric palliative care focuses mainly on the children suffering from a life-limiting disease, but always includes parents and siblings. However, grandparents are also often highly involved in caring for the child and require additional attention. Therefore, the aim of this study was to investigate the experiences of grandparents during the end-of-life care and after the death of a grandchild.

**Design and methods:** A qualitative approach using semi-structured interviews was chosen. Fifteen grandparents of 10 children who had died of neurological or oncological diseases were interviewed. Participants were recruited among the families cared by the pediatric palliative care team of a children's hospital in northern Switzerland. Grandparents were interviewed at least one year after the death of the grandchild. The data was analyzed employing reconstructive interview analysis.

**Results:** Regardless of the child's diagnosis and circumstances of death, the participants described how the child's death had a major impact on them and their entire family. Grandparents felt obligated to support the family and constantly be a source of support for the parents. They bore a heavy psychological burden as they cared and mourned not only for their dying grandchild but also for their own daughter or son. Grandparents struggled with their ability to communicate about disease and death. They tried to process and make sense of their loss by remembering the deceased child.

**Practice implications:** These findings emphasize the importance of identifying and understanding grandparents' suffering. Pediatric palliative care teams can achieve this by actively making contact with grandparents, taking their concerns seriously and demonstrating appreciation for their role in supporting the family.

**Keywords**

Grandparents, pediatric palliative care, death, bereavement, child

**What is currently known?**

Dealing with a life-limiting disease and the death of a child has an enormous impact on the whole family. Grandparents are often essential supporters of the affected family.

Grandchildren play an important role in the grandparents' lives, they guarantee that the family will continue to thrive generationally. Grandparents take pride in their grandchildren.

**What does this article add?**

For the first time in German-speaking countries, the experiences of grandparents throughout a child's illness—from diagnosis to the time of death and bereavement phase—is described. Data analysis in this study shows that grandparents feel obligated to support their children's family during the illness and even after death. Our study illustrates the uncertainty grandparents are forced to live with due to unexpected deterioration or abrupt death of the child, or sudden psychological destabilization of their own children.

## Introduction

Illness is a family affair, especially in the case of children with a life-limiting disease (Wright& Leahey, 2005). Family members are important care partners for the nurses and the interprofessional treatment team at the hospital. This includes grandparents, who often play an essential role in pediatric care. They look after the affected child and/or the siblings, and they provide practical and emotional support for their own children, the parents of the sick child (Woodbridge, Buys& Miller, 2011).

The death of a child is rare; in Switzerland approximately 500 children die each year. Beyond the first year after birth, the most common cause of childhood death is accidents, followed by neurological and oncological diseases (Federal Statistics Office, 2017).

In pediatric oncology, the palliation phase is normally quite short. Even if curative therapy is no longer available, diseases can be controlled to some extent by palliative chemotherapy or radiotherapy. After the onset of distressing symptoms, death usually occurs within a few weeks (Bergstraesser, 2014).

On the other hand, for the group of neurological diseases, palliative care often starts with the diagnosis due to the degenerative character of these diseases and/or the lack of therapeutic options. The palliation process can last months or years. Affected families are confronted with the fluctuating health problems of the child and persistent uncertainty (Bergstraesser, 2014).

For many Swiss families, grandparents play a crucial role. Particularly when both parents work outside the home, and due to the limited availability of daycare facilities in Switzerland, a large proportion of families are dependent on the support of grandparents for childcare (Bauer, Strub, 2002).Grandchildren are often an important aspect of grandparents' lives; they guarantee that the family will continue to exist generationally. Grandparents take pride in their grandchildren and it is important to them to pass their knowledge and values on to their grandchildren (Höpflinger, Hummel& Hugentobler, 2006).

Despite their key role in the family, there is a lack of knowledge on the experiences and needs of grandparents when their grandchild is diagnosed with a life-limiting disease. Studies performed in English-speaking areas and Israel have shown that the burden can be enormous (Lauterbach, 2002, Gilrane-McGarry& O`Grady, 2012, Torjeman, Doron& Cohen, 2015, Youngblut, Brooten, Blais& Kilgore, 2015, Wakefield, Drew, Ellis,Doolan, McLoone et al., 2014). However, existing studies have focused either on the experiences of grandparents during the disease or on the loss of a grandchild. This study aims to specifically explore the experiences of grandparents during the end-of-life care phase and after the death of a grandchild who was suffering from a neurological or oncological disease.

## Methods

Design and participants

To answer this research question, a qualitative study was carried out using problem-focused interviews. The purpose of this interview method is to capture a particular social situation that all participants share (Hopf, 2004).

Participants were selected by means of purposive sampling. Inclusion criteria were: grandchild's death being at least one year and at most five years prior to the interview, and the ability to respond to questions in German. The parents of 35 children with an oncological or neurological disease, treated until death at a children's university hospital, were contacted by letter and asked to inform either the maternal or paternal grandparents about the study. Grandparents from 13 deceased children were interested in taking part in the study. Two potential participants had to be excluded.

Table 1 shows sociodemographic characteristics of the participating grandparents. A total of six grandmothers, one grandfather and four grandparent couples were interviewed. Four of the children died from an oncological disease and the other six children due to a neurological condition. Diagnoses in the group of the oncological diseases were either leukemia or a brain tumor. The group of neurological diseases showed a variety of six different conditions.

Insert Table 1 sociodemographic data here

Data collection

The interview guideline (Table 2) was developed by two experienced, female qualitative researchers (MF and CO) based on the literature and conversations with

affected grandparents. The guidelines were tested beforehand with one of the grandmothers. If the grandparents brought up new topics in the interviews, these were included in the guidelines for subsequent interviews. Participants were interviewed at home during the summer of 2017. Four grandparents wished to be interviewed together with their spouse in order to provide support for each other while talking about the experience. The interviews were conducted, audiotaped and transcribed by the first author. Some of the participants were known to the interviewer from short interactions at the hospital. The interviewer explicitly explained to these participants that she was interested in the narration of the story from their own perspective.

Insert Table 2 Interview guide here

Data Analysis

Data collection and data analysis were conducted concurrently; this allowed the exploration of new themes that were brought up in subsequent interviews. The audiotaped interviews were translated from Swiss-German dialect into Standard German, and transcribed including pauses and intonation. They were analyzed using the integrative interview analysis method, which integrates techniques from the grounded theory method, the ethno-methodological conversation analysis methods, as well as Manheim's documentary method, in a reconstructive-hermeneutic analysis process (Kruse, 2015). Meaning in the interviews is reconstructed based on the analysis of linguistic phenomena, communication patterns and interactional aspects. First, individual cases were analyzed in a sequential and detailed reconstructive process. Second, a comparison process between the interviews took place in order

to identify primary common patterns and themes across interviews (Kruse, 2015). Finally, main themes were condensed into central categories in team meetings in which the final interpretation of the results took place.

The data were analyzed by a peer group of four researchers supervised by a senior researcher (EB). To enhance the credibility of the results (Creswell, 2014), a summary of the results was sent to two participants in order to ensure validity of the results through member checking. The reported results of this study met the consolidated criteria for reporting qualitative studies (consolidated criteria for reporting qualitative research (COREQ, Appendix 1)).

### Ethical considerations

The research project was approved by the Ethics Committee of the Canton of Zurich (vote: 2017-00266, date: 19 April 2017). All participants received an information letter and signed their informed consent. In addition, grandparents were offered the chance to contact the psychologists of the pediatric palliative care team if they needed help with emotions arising after the interview.

## Results

Figure 1 gives an overview of the central categories that emerged from the interviews. They are described below.

Insert Figure 1 here

Dealing with the child's suffering, experiencing how the entire family system was destabilized, feeling obliged to support the family and being confronted again and again with challenging encounters were issues that all grandparents brought up in the interviews, regardless of the diagnosis of the affected child.

Dealing with the child`s illness and death.

Some of the grandparents suspected in advance that something was wrong with the grandchild. For others, the diagnosis of a life-limiting disease was completely unanticipated. All grandparents described the painful symptoms from which their grandchild suffered. For grandparents whose grandchild suffered from a neurological disease, the most painful symptoms were seizures, recurrent infections or pain. With children suffering from cancer, symptoms were caused by the side effects of chemotherapy or the uncontrollable progression of the disease: *"He was an incredibly beautiful 'little boy'; [he had] such charisma [and was] so radiant. Seeing the body changing through the disease and the necessary treatments was really hard."* (Interview 5).

The symptoms made the grandparents feel helpless when they realized that they could not help their grandchild. Their suffering was increased by a permanent uncertainty: *"My heart was always racing when I went to their place. I always wondered: what is going to happen today, hopefully nothing bad has happened, [...] is he in stable condition or has he gotten worse?"* (Interview 1). Regardless of the diagnosis of the child, grandparents repeatedly found themselves saying goodbye to

their grandchild because it was never clear if it would be the last time they would see him/her.

**Watching family destabilization**

Regardless of the diagnosis and circumstances of the child's death, grandparents described the enormous impact that the disease and the child's death had on them. Caring for the child at home could be so complex that people outside of the family were afraid to take care of the child. The family therefore had to cope with the entire burden itself. Due to the treatment with visits to the hospital, both scheduled and emergency visits, the disease had an impact on the whole family organization. The grandparents also reported the serious consequences of the child's death on the family: "*And then it was as if a bomb had hit us, everyday life and their relationship, everything dissolved*" (Interview 1). In some cases, the parent`s relationship would fall apart or the they would lose their jobs.

Beside the destabilization, the grandparents also mentioned positive results, such as increased cohesion in the family and learning to approach people with disabilities in a completely different way.

**Feeling an obligation to support**

The grandparents felt obligated to support their child's family in this situation. This support obligation arose the moment the grandchild was diagnosed with the life-limiting disease: *"I would have felt guilty if I had just abandoned them. No, I couldn't have done that"* (Interview 6). They were willing to travel long distances or put their own work on hold.

The grandparents cared for the affected child; they looked after the healthy siblings and provided practical support in the household. They also felt obliged to provide emotional support. The grandparents were not only constantly worried about their grandchild, but also about their own child (one of the parents). They wished that they could relieve their child from the heavy burden. These worries about their own child did not cease after the death of the grandchild. They experienced the serious emotional crises their child was going through. It was difficult to muster strength for further support in the middle of their own grief: *"I told my daughter: 'I think you have to go to a psychiatrist, someone who can help you, because I have NO strength left, [...] I don't know how to help you anymore'."* (Interview 11).

They were also concerned for the deceased grandchild's siblings, as they feared that the events could have a negative impact on their development: "*Emma, of course, missed out. She was six months old when Michael fell ill. She was one and a half years old when Michael died and during this time she missed out on attention" (Interview* 10). The obligation to support was so strong that grandparents, even when asked about wishes for themselves, formulated needs for their child. They wished, for example, for a more proactive approach by the treatment team, e.g. in the diagnostic phase, especially in families where the sick child's parents refused to accept the child's symptoms at the beginning. They also expressed their wish for earlier psychological support for the parents of the child. For the grandparents it was also important that the palliative care team continued to support the whole family after the child's death.

### Challenging interactions with grandchildren, family members, acquaintances and health care professionals

When grandparents talked about the child's illness and death with others, the experiences ranged from an open culture of communication, for example within their own family, to very hurtful reactions from acquaintances. Some felt that they were kept up to date by their child during the illness, but that after death it was no longer possible to talk about the deceased grandchild because the parents banned conversations on the topic.

The grandparents openly spoke about the disagreements that arose between them and their children in the course of the illness and after the death of the grandchild. During the illness, for example, they had differing views on therapies, and after the grandchild's death they disagreed, for instance, on mourning rituals.

Even though it was natural for them to provide support to their children, it was a permanent balancing act between providing help and not interfering. They realized that too much of a helping attitude could also endanger the relationship with their children: *"I think the most difficult thing for grandparents, when they have a handicapped grandchild, is finding the balance to discern: 'where do I hang in and where do I stay out?'" (*Interview 4).

Grandparents reported experiencing grief even before the death of the child, namely from the moment when the family was forced to accept the life-limiting disease and had to deal with the imminent death of the child. After the grandchild's death, all grandparents were involved in the farewell rituals. It could be distressing for the

grandparents when funeral traditions considered important were not followed: "*They have no grave, they have the urn at home."* (Interview 2).

The grandparents were also confronted with different reactions from their social environment. It was hard for acquaintances to imagine what it meant to care for a child with a life-limiting disease. Sometimes the grandparents experienced empathy and compassion for their situation, but there were also very hurtful reactions:

> *Two months after the death of Sina, a neighbor asked, 'How are you?' and I said 'So far [I'm] well, but it is still difficult and also sad; we loved Sina.' Then he said, […] 'Yes, yes, but she was a handicapped child, nobody can make me believe that you miss her THAT much' [...]. I was totally shocked* (Interview 4).

Grandparents also talked about the staff members they met either at the hospital or as members of the community nursing team. They reported having had only a few direct interactions at the hospital, as they often had to take care of the sick child during conversations between the parents and the hospital team. The grandparents appreciated it when their commitment was perceived and acknowledged by the treatment team. They reported feeling comforted when they found out that the death of the child had also affected the staff members:

> *And I arrived at the hospital and doctors in white scrubs came up to me with tears in their eyes and they asked, 'Are you the grandmother?' 'I am' [I said]. They said, 'We tried everything, but we couldn't save Gabriel.' (Interview 1).*

Impact on grandparents

Regardless of the diagnosis and the circumstances around the death of the grandchild, the events had a major impact on the grandparents. As they had put their lives on hold for a long time, some of them only became aware of the effects after the death of their grandchild.

Some of the grandparents struggled with health issues and felt completely exhausted: “*After the death of the grandchild, I fell into a depression”* (Interview 3). Not only did the child's parents take a long time to adapt to the new situation after the child's death, but the grandparents also realized how all-consuming it was.

The linguistic patterns used in the interviews revealed that the grandparents tried to give meaning to what had happened. All of the grandparents described their grandchild as someone special. The grandparents expressed gratitude for the short time they were allowed to have with the child. Grandparents struggled with the fate that the family had to face and were rather convinced that it should have been their turn to die: *“Somehow the order of being born, living and dying has not been kept."* (Interview 7). Grandparents talked about the missed future of the grandchild, e.g. missing the opportunity to experience how the child would grow up. They found solace in thinking that the early death had spared the child many other painful symptoms and spared the family further suffering.

When asked what had helped them through this difficult time, they first named the deceased child, and then the other grandchildren. They described the support of friends and the strength they drew from physical activity, music and nature.

They also found comfort in symbols. A grandmother who lost her grandchild due to a neurological degenerative disease said: "He was like *a butterfly that went back into its cocoon again."* (Interview 1).

The interviews revealed implicit wishes, such as the need to be able to describe the events in detail, and thus the need to be heard. They discussed the illness and the death as if it had been yesterday. The language used by the grandparents during the interviews was vivid and the interaction with the interviewer was shaped by narrative plots intended to introduce the interviewer to their experience as intensely as possible. This can be interpreted as a need to express themselves and share their story.

Despite coping strategies, the grandparents agreed that this event was the most upsetting experience of their lives: "*I've had a good life; this is the worst that [has] happened [to me] in 86 years."* (Interview 7). They were aware that they would carry this serious event with them throughout the rest of their lives.

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## Discussion

Regardless of the child's diagnosis and circumstances of death, the participants described how the child's death had a major impact on them and their entire family. Grandparents felt obligated to support the family and constantly be a source of support for the parents. They bore a heavy psychological burden as they cared and mourned not only for their dying grandchild but also for their own daughter or son.

While other studies describe either the time during the child's illness (Wakefield et al., 2014, Woodbridge et al., 2011) or the time after the child's death (Gilrane-McGarry& O`Grady, 2011, Gilrane-McGarry& O`Grady, 2012, Youngblut et al., 2015), this study describes the effects of the grandchild's life-limiting disease on grandparents from diagnosis to bereavement. To our knowledge, this is the first study in a German-speaking country to investigate the experiences of grandparents who were faced with the death of a grandchild.

Regardless of the diagnosis and circumstances of death, the grandparents in this study described the severe effects that this event had on them personally and on their families. Grandparents felt obliged to support their child's family from the time of diagnosis, during the illness and through to after death. During the grandchild's illness, they cared both for the well-being of that grandchild and for their child's whole family. After the death of the child they supported the family further, e.g. by helping to organize the farewell rituals and taking-up daily life again.

The grandparents mourned doubly: for the deceased child and for the young family hit by this loss. They experienced how communication was a challenge regarding the

child's illness and death, not only within the family but also with friends and acquaintances. The grandparents struggled to make sense of what had happened. They tried to find comfort by taking part in the mourning rituals in the family and by remembering their grandchildren.

Höpflinger (2010) describes the social norm that grandparents should not interfere in the upbringing of their grandchildren. Our interviews revealed that compliance with this social norm was more difficult to achieve when the parents depended on the support of the grandparents. Therefore, the risk of conflict through too much interference was a central issue for this study's participants, which has been also confirmed by other studies (Wakefield et al., 2014, Woodbridge et al., 2011, Gilrane-McGarry& O`Grady, 2011, Gilrane-McGarry& O`Grady, 2012). This finding is in line with the model of intergenerational solidarity of Szydlick (2008), which explains how a balance between solidarity and conflict avoidance must be maintained within families.

One new finding of this study is the uncertainty that grandparents had to live with, considering that they never knew how their encounters with the sick child would be, due to constant health status changes. A related finding, confirmed by Hillen, Gutheil, Strout& Smets (2017), revealed that living with constant uncertainty and fear that something bad will happen can increase the vulnerability of the grandparents.

The theme of double mourning addressed by all grandparents has been reported in previous studies (Gilrane-McGarry& O`Grady, 2012, Tourjeman et al, 2015, Wakefield et al., 2014, Youngblut et al., 2010, Nehari, Grebler& Toren, 2007). The grandparents' concerns about the wellbeing of their child also influenced

communication within the family. Although communication became more difficult after the grandchild’s death, in the study at hand, none of the grandparents reported that their relationship with the parents had broken off, as was found in another study (Nehari, Grebler& Toren, 2007). Social support from other mourning family members and friends is an essential factor in coping with mourning (Stroebe& Schut, 2001). The grandparents in this study experienced a great deal of support, but also distressing reactions up to a total lack of sympathy when outsiders questioned grandparents' affection for the deceased child. They realized that the death of a grandchild is not a topic for small talk.

The grandparents described their deceased grandchild as special and the relationship as very close, despite the short life of the child. This finding reflects the strong need for coherence and meaning which the grandparents were striving to cope with after losing their grandchild. This strong need becomes plausible when framed against other findings that have pointed to the lack of coherence stemming from the death of a grandchild, since it implies an inversion of the natural order of things (Gilrane-McGarry& O`Grady, 2011, Tourjeman et al, 2015, Nehari et al., 2007, Woodbridge et al., 2011, Youngblut et al., 2010). Grandparents were deprived of the opportunity to continue to transmit cultural and social values to the child, an important element of intergenerational socialization (Lüscher et al., 2010). For the grandparents, inclusion in the mourning rituals was an important element of the acceptance process, something that was withheld from the grandparents in the study by Tourjeman et al. (2015), where the grandparents were not allowed to take part in the farewell ceremony. In this study, the grandparents also sought refuge in

comforting pictures, which can be regarded as one of many strategies used to cope with their grandchild’s death.

**Strengths and limitations**

Although at the beginning only individual interviews were planned, some grandparents asked to be interviewed together with their partner, and we noted that they triggered each other’s memories during the interview process. The extensive openness that the grandparents showed confirmed the suitability of this change in the protocol and of the interview method. The large variance in the ages of the children, the diseases described and in the circumstances of death of the deceased child yielded a wide spectrum of perspectives. A further strength is the fuller account of the grandparents' experiences over the entire time span, from the diagnosis of the life-limiting disease to the death of the grandchild. To check for plausibility as recommended by Giacomini and Cook (2000), the results were presented to two affected grandmothers. Both confirmed that their own experiences were well reflected in the interpretation of the results.

It cannot be ruled out that the participants who already knew the interviewer omitted relevant information because they thought she already knew about it. Further, the deductive sampling might have resulted in a selection bias because the parents decided whether or not they wanted to pass the information letter on to the grandparents. It cannot be ruled out either that grandparents who were more

positively engaged in family life of their child were the most likely to respond. Finally, the interviews, which were conducted in Swiss dialect had to be transcribed into Standard German for the analysis, which could lead to a loss of contextual information. This is especially notable from the fact that the method applied pays special attention to linguistic phenomena, e.g. use of everyday language to express feelings (Kruse, 2015).

**Implications for practice and research**

Further qualitative studies are necessary in order to comprehensively explore the experiences of grandparents who have lost a grandchild to a neurological or oncological disease. In addition, investigations on grandparents who have lost a grandchild due to other causes of death—such as cardiological diseases or premature birth—could lead to further significant insights.

However, based on the results of this study, it is safe to assume that members of the treatment teams should assess the role and duties of the grandparents within the family. Parents can be asked how they plan to inform the grandparents about the poor prognosis and whether they would like to receive support during the process. Since the grandparents often provide their support in the background, a printed information brochure could also be a way to reach them. The sensitization of the treatment team to the experiences and needs of the grandparents—especially the issues of double care and grief and the resulting need to support their child's family—appear to be of central importance. In direct contact with the grandparents, the members of the treatment teams should consciously address these issues. The

perception and appreciation of the grandparents' role in these difficult situations could become a standardized step in care.

## Conclusions

For the first time, the present study depicts the situation of grandparents during the illness and death of a grandchild with a life-limiting disease. We show the importance of understanding and identifying grandparents' suffering. Pediatric palliative care teams can achieve this by actively making contact with them, taking their concerns seriously and demonstrating appreciation for their role in supporting the family.

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## Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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## Tables

**Table 1.** Sociodemographic data

| | |
|---|---|
| **Participants** | n=15 |
| Grandmothers | n=6 |
| Grandfathers | n=1 |
| Couples | n= 4 |
| **Age range participants** | 60-86 years (Median 69 years) |
| **Marital Status** | |
| Married | n=11 |
| Divorced | n=4 |
| **Deceased children** | n=11 |
| Age range at time of death | 7 month- 13 years |
| Oncological disease | n=4 |
| Leukemia | n=2 |
| Brain tumor | n=2 |
| Neurological disease | n=6 |
| Encephalopathy | n=1 |
| Morbus Tay Sachs | n=1 |
| Cerebral palsy | n=1 |
| Infantile Spasm (West Syndrome) | n=1 |
| Vactrl association | n=1 |
| Neural tube defect | n=1 |
| **Interview duration** | 65-90 minutes |

**Table 2**. Interview guide

| **Main guiding questions** |
| --- |
| Opener: To start, I would like to ask you to tell me the story of your grandchild from your own perspective. |
| How were you integrated into the family of your son, your daughter, at the time of diagnosis and illness? |
| Can you tell me more about how you experienced the palliative care of your grandchild? |
| May I also ask you to tell me how you experienced the death of your grandchild? |
| How did you experience grief for your grandchild? |

If you look at the whole time of illness, death and the time after the death of your grandchild: What support did you personally receive during this time?

If you look back at the whole time, what were the effects/ consequences of the whole event on you/ the family? And how are you / your family today?

Thank you for your time and openness.

## Figures

Figure 1